

Professor Evans discussed her work as part of a National Institute of Health-funded panel that will include exploring ways to ethically use personal health information as part of health research, how to share data across national boundaries, and how to lower the cost of health research while improving its quality.

This article appeared in the Indiana Daily Student on Tuesday, October 27, 2009:

NIH awards IU grant for privacy in health research

Privacy in the Information Age might be getting more secure.

The National Institutes of Health awarded \$538,595 to the Center for Applied Cybersecurity Research at IU to look for ways to improve privacy in health research. Law professor Fred Cate, director of the CACR, said the center will assemble a panel of experts to examine privacy issues.

The project, titled "Protecting Privacy in Health Research," will bring together a diverse panel of experts in the fields of medical research, law, ethics and patient advocacy to wrestle with the issue of how privacy should be protected, he said.

Currently, health researchers must follow privacy regulations outlined by the Health Insurance Portability and Accountability Act's "Privacy Rule," which Cate said he believes is causing a lot of problems for researchers.

"What we're trying to do is come up with a better approach," Cate said. "That doesn't mean the perfect approach, but something that would free up the health researchers from these requirements that don't do much to protect privacy, but that have tremendous amounts of cost to getting the job done."

Over the course of two years, the panel will work together to address issues expressed by the Institute of Medicine Committee on Health Research and the Privacy of Health Information, who argue for a new regulation that would exempt health research from the HIPAA Privacy Rule.

The issues the panel will address include finding ways to share data across national boundaries as well as ways to ensure that personal information given by the public for research will be protected, said Barbara Evans, panel member and director of the Center on Biotechnology and Law at the University of Houston Law Center.

The group will also look into the ethical aspects of controlling data in health research that has been de-identified, wherein a person's name and identifying information have been withdrawn.

"The problem we're encountering in medical science is that we need access to data, but you know how you would feel if you hear your medical records had been taken to be used in a study," Evans said. "You'd be concerned about it."

With breakthroughs in genetics and genetics medicine, it has become increasingly important to have access to tissue specimens and previous research, she said. Evans said the panel will be looking for ways to create a system of ethical protections.

She said the panel also hopes the project will help to find ways to lower the cost of health research as well and improve the quality of the research performed.

The money from the grant itself will be used to assemble the panel and educate the public on their progress through online distribution and a series of conferences, along with producing a final report that Cate said he hopes to complete by May 2011.

“It’s going to be a lot of hard work but it’s really important,” Cate said. “Because otherwise we’re missing the chance to do research that can save people’s lives.”